

Testimony Regarding
H.B.5303: *An Act Concerning Continuing Medical Education Requirements Concerning Endometriosis and Cultural Competency and the Creation of a Plan for an Endometriosis Data and Biorepository Program.*

March 9, 2022

Emma O. Heintz

To co-chairs Senator Abrams, Representative Steinberg, and distinguished members of the Public Health Committee, My name is Emma Heintz. I am a current graduate student studying policy practice in social work at UCONN and I also have a bachelors in Women and Gender Studies. Today I am speaking on behalf of H.B.5303: *An Act Concerning Continuing Medical Education Requirements Concerning Endometriosis and Cultural Competency and the Creation of a Plan for an Endometriosis Data and Biorepository Program.*

While I have focused my passions to promote feminist objectives, my sister has dedicated her passion to science and is currently researching Endometriosis at Boston Children's Hospital in the Roger's Lab. It's not surprising that we often share lengthy conversations on the subject of endometriosis, even more so now that we are both under the process of being diagnosed with it.

My sister and I have talked about how endometriosis, as a disease, has been overlooked by the medical community, legislators, and by society as whole due to its association with the female sex¹. We have even talked about how this experience is worse for women of color², as well as how difficult it is to get research funding³. My sister has seen firsthand how cis-male centric medical research is⁴.

I have confided in her my experience with doctors, gynecologists, my menstrual cycle, dysmenorrhea, and dyspareunia throughout my life. And now I will share some of that experience with all of you:

When I started menstruating in middle school it was unpredictable and painful. However, it started to feel like every time I got my period it got worse and worse. One morning in my freshman year of high school I woke up with such bad menstrual cramps that I vomited from the pain. For what felt like the rest of high school I would miss school at least once during my menstrual cycle every month.

When I finally talked to my pediatrician, her solution was to prescribe pain medication. Then when I was 16 my pediatrician recommended the birth control pill. As a 16 year old the only thing I knew about the pill was that it prevented pregnancy. What I did not know was that the birth control pill my doctor gave me was an estrogen-based form of birth control. My sister and

¹ Hudson, N. (2021, August 13). *The missed disease? endometriosis as an example of 'undone science'*. Reproductive biomedicine & society online., from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8517707/>

² Ibid

³ Glenza, J. (2015, September 28). *Endometriosis is often ignored as millions of American women suffer*. The Guardian. from <https://www.theguardian.com/us-news/2015/sep/27/endometriosis-ignored-federal-research-funding>

⁴ ibid

many other scientists/doctors who have studied endometriosis will say that it is an estrogen-dependent disease⁵ meaning that an estrogen-only birth control wasn't going to alleviate my suffering. There were so many things I missed out on due to my extreme menstrual pain, but it mostly impacted my education.

When I finally went to see a gynecologist, she refused to give me a pelvic exam because she thought I was too young. She refilled my estrogen-only birth control pills and I went on to suffer, coping with the pain with aleve. When I saw a new gynecologist at 21 she switched my birth control to a combination pill, with the hopes that it would help alleviate my extremely painful menstrual cycles. While the change did help I continued to suffer from chronic pelvic pain, back pain, and dyspareunia which are all signs of endometriosis⁶. In 2020, my gynecologist finally suggested that I may have “*a touch of endo*” and I was supposed to have a pelvic laparoscopy done, but the Covid-19 pandemic prevented it.

My sister and I have talked about how I am not alone in my experience, but many people with uteri have medically misunderstood. Therefore it is not surprising that it can take up to 10 years to receive an endometriosis diagnosis and that many individuals are misdiagnosed⁷. Supporting this bill will help change dynamics of how this painful disease is handled, so that individuals like me are not medically misunderstood for years, and receive proper diagnosis and treatment at a younger age.

Thank you for your time and consideration,

Emma O. Heintz

⁵ Yale Medicine. (2019, October 30). Endometriosis. Yale Medicine. from <https://www.yalemedicine.org/conditions/endometriosis#:~:text=One%20of%20the%20most%20common,there%20may%20be%20no%20symptoms>

⁶ Amber et al (2020) Investigating the role of infertility in endometriosis risk,

⁷ Yale